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ABSTRACT

This paper reviews literature and clinical experiences on the neurobiological and psychological aspects of sleep in children with mental retardation. The lack of a universal, operational definition of sleep disorders is noted, and a study is cited in which 61% of a group of 20 children (ages 2-13) with developmental disabilities were found to have sleep problems. DIMS (disorders initiating and/or maintaining sleep) is discussed as a frequent type of sleep problem, with emphasis on the need to establish a consistent behavioral routine prior to sleep onset and the need to gradually and systematically "shape" the child to remain in bed and return to sleep. Other sleep disorders discussed include nightmares, night terrors, and excessive sleepiness/sleep stage abnormalities. (12 references) (JDD)

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PSYCHOLOGICAL ASPECTS OF SLEEP DISORDERS IN CHILDREN WITH MENTAL RETARDATION

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Paper presented at the 115th Annual Meeting of the
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ABSTRACT

The incidence of sleep disturbance in children with mental retardation and various handicapping conditions (e.g., autism) has, with some debate, been generally reported to be higher than in children without mental retardation. Sixty-one percent of a sample of children seen at an interdisciplinary assessment clinic were found to have some sleep problems, suggesting the need for professionals in the field of mental retardation/developmental disabilities to be informed of the current literature. Some of this literature is reviewed, along with reports of case studies, which emphasize the need for an accurate discernment of which features constitute neurological phenomena and which may represent behavioral/learning problems.

Since the 1950's pioneers such as Nathaniel Kleitman and William Dement have made major breakthroughs studying the physiology of sleep, leading to a plethora of normative data that has greatly aided the understanding of the stages of sleep and its disorders. Most major communities in the United States now have at least one sleep disorder clinic or laboratory, taking the investigation of sleep from the research arena to that of clinical application. Although the literature studying individuals with mental retardation and sleep disorders is somewhat less prolific, a growing body of information exists for theoretical and practical uses (Okawa & Saki, 1987). Sleep disorders, in their various forms, often become a concern for parents of children with mental retardation. An accurate discernment of what constitutes neurological phenomena and what may represent behavioral/learning factors is critical in the process of understanding and treating them. The purpose of this article is to share some of this current literature and clinical experiences on the neurobiological and psychological aspects of sleep in children with mental retardation.

The incidence of sleep disorders in children with mental retardation is not well documented. One reason may be the lack of a universal, operational definition of sleep disorders. The debate about what represents pathological conditions and what may be normal aspects of the developing child arises, particularly when reports that 15 to 35 percent of young children show problems either resisting going to sleep or awakening during the night (Ferber, 1987). Whether we are merely talking about a disorder or an annoying part of early child development (which becomes extended in the developmentally delayed individual) is

probably irrelevant to the parents fighting with their children at bedtime, and perhaps developing a sleep disorder of their own. A sample of children brought to a University-Affiliated Developmental Disabilities Program for an interdisciplinary assessment, some of whom have sleep difficulties, can possibly give an estimate of the extent of the problem. A random sample of 20 children, ages 2 to 13, resulted in 61% showing some level of sleep problems, according to parent report during the Pediatric or Social Work evaluation. Sleep problems were defined as children who either had trouble falling asleep or awakened at least twice a week over a period of four or more weeks. Thus, professionals in the field of developmental disabilities are challenged to be aware of the data and issues involved.

Common Sleep Disorders in Children with Mental Retardation

A brief overview of some of the common sleep disturbances encountered by children with mental retardation will be discussed. Preferatory remarks are imperative concerning the need to have medical or physical aspects ruled out before one hypothesizes about psychological causes. A first analysis of any problem around sleep requires the medical assessment of whether a clear biological/physical etiology can be determined. Everything from acute illnesses (e.g., ear infections) to respiratory obstructions need to be investigated. Undetected epilepsy and side effects from pharmacological interventions would also need to be considered. Assuming that these medical issues have been ruled out, other factors interfering with normal sleeping can then be investigated.

DIMS. A frequent type of sleep problem is categorized as Disorders Initiating and/or Maintaining Sleep (DIMS). Whether a parent is complaining about multiple "curtain calls" or the irritating circumstances of a child who chronically awakens at 2 a.m., in need of adult attention, DIMS challenge the parent and clinician. Petre-Quadens (1972) reported that children with mental retardation generally showed shorter sleep time compared to children without mental retardation. Assuming that there is no medical aspect to account for the problem, difficulties in this area often involve failure of the child learning to independently fall asleep and/or return to sleep. This unlearned skill can be the result of poor and inconsistent limit-setting, where the parents' inability to be authoritative (Baumrind, 1984) leads to DIMS. Thus, the parent who inconsistently follows through on bedtime rules, is over/under firm in his limit-setting, or simply becomes indulgent in his expectations about where and when to sleep will create disruptions in a child's sleep onset and cycles. The good-intentioned parent who is regularly attending to the oppositional or distressed child may very likely be reinforcing the maladaptive pattern. Intervention about the foundations of behavioral management is likely best in these circumstances, rather than simply targeting the sleep issues as an intervention focus.

When maladaptive sleep habits have developed, yet the parents are otherwise effective limit-setters, the appropriate intervention recognizes the integration of biological and learning aspects.

Certainly, an understanding of the sleep cycle and circadium rhythms is tantamount to shaping appropriate sleep hygiene in children. Figure 1 shows the normal progression of sleep stages, which become regularly and properly sequenced for most children after the establishment of a consistent schedule of beginning and ending sleep. Children who are placed to bed at different times each night or must awaken at varied hours will not be able to establish the consistent pattern, required for the proper amount of important deep sleep and Rapid Eye Movement (REM) stages to occur. Excessive drowsiness during a subsequent day of shortened or disrupted sleep may even lead to a late afternoon nap, which can further disrupt the sleep cycle as the body attempts to make up for the stages deprived, further affecting the sleep cycle. The implementation of a regular time for sleep onset and awakening allows the child's sleep cycle to be well integrated with his or her circadium rhythms, which will increase the odds of greater physiological preparedness for sleep and more regular cycles.

Establishing a consistent behavioral routine prior to sleep onset has also been found to be useful for facilitating the child's drowsiness and quick emersion into sleep. A sample of North American 2-1/2 years olds showed that 90% have some form of a routine established before sleep (McFarlane, Allen & Honzik, 1954). Many of the routines and transitional objects act as conditioned stimuli to activate drowsiness, as they are regularly paired with the eventual onset of sleep. Curiously, some children with mental retardation will establish their own "rituals", using rocking behaviors or some other stereotypic responses prior to falling asleep. A typical bedtime routine might

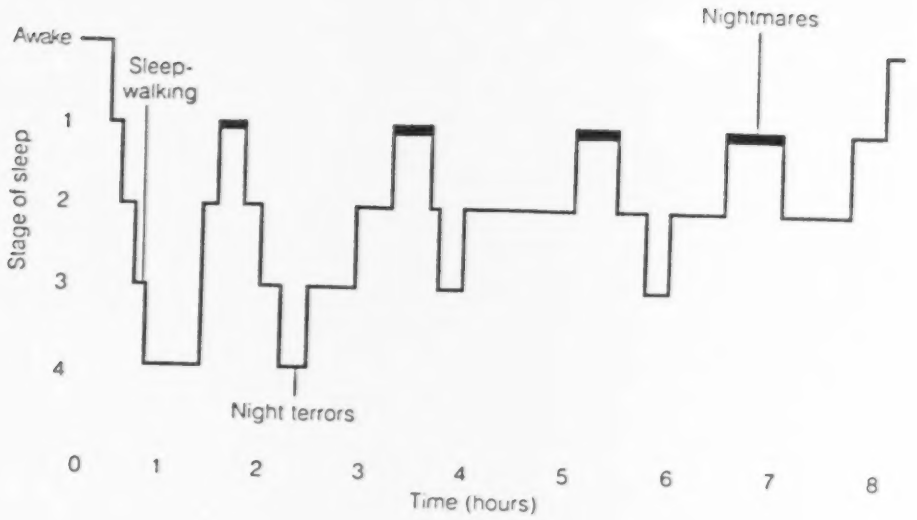

Figure 1 Sleep problems and the cycle of sleep. Different sleep problems tend to occur at different points in the sleep cycle. Whereas sleep-walking and night terrors are associated with deep, non-REM stages of sleep, nightmares are associated with the heightened dream activity of REM sleep. (From Weitan, 1989).

involve a snack (i.e, preferably a milk product), toileting and bathing activities, reading several books, and prayers/singing songs while in bed. These events become a predictable pattern that helps the child during this transition period, and similarly pairs the events with the drowsiness for establishing proper conditioning. Parenthetically, built into this routine are a number of privileges, which can be used for leverage when the child begins to stall or become noncompliant. For example, the warning that a loss of one of the books or a song conditional upon either the child getting out of bed or failing to brush teeth, can be used and followed through upon to elicit greater compliance.

One 5-year-old child with autism and mental retardation was observed in a Diagnostic Classroom at our center for a period of 10 weeks, during which a pattern of daytime drowsiness was noted. Contacts with the mother indicated that he had recently begun to show severe problems going to sleep at night. Assessment at a local sleep disorders laboratory essentially diagnosed the mother's recent hospitalization, for the birth of a child, to have likely been the precipitator that disrupted his routine. Even when she returned to the home and reinitiated the previous schedule, he was not able to reestablish his prior pattern of sleep onset very quickly.

Curiously, while transition objects or comfort articles can be made part of the bedtime routine, some researchers have discussed the use of a pacifier to be contraindicated (Ferber, 1987). Particularly in a child beyond age 2, the sucking on the pacifier requires effort that

can maintain arousal so as to delay sleep. Also, the onset of deeper sleep stages will usually stop the sucking, which leads to arousal and awakenings that become "pacifier patterns" which can disrupt the normal acquisition of the sleep stages.

Awakenings during the night, apart from those precipitated by sleep apnea, can be fairly normal. The awakenings usually occur in between stage 2 and REM sleep (see Figure 1) and most children beyond a certain age will return to sleep on their own. A clinical interview should seek to determine whether the awakenings appear to be of a primary or secondary nature. Primary awakenings occur with children who have never had a sustained period of at least a month where they are able to remain asleep for the entire evening without adult intervention. Those with secondary awakenings are children who show an acute period of requiring parent assistance to help them return to sleep. While the primary types are typically a result of learned and/or medical factors, the secondary types are very often paired with acute stressors or situational variables. Depression, anxiety, an acute cold, or distress from changes in one's daytime routine or sleep schedule are possible causes for secondary awakenings.

The typical process to help one learn to fall asleep involves a gradual and systematic shaping of the child to remain in bed and learn to return to sleep. Eight to nine-month-old infants can usually learn within a few days or weeks to "cry it out" as they become reassured with increasing time intervals without being picked up. The older child with mental retardation becomes somewhat more challenging because

of their ability to come out of bed, yet the parents' consistent insistence for the child to remain in bed can often gradually condition the return to sleep. Some of the cases have required installation of door locks from the outside of the bedroom in order to prevent nighttime roamings.

An example is an 8-year-old male, with moderate mental retardation and deleted material on the 17th chromosome, who had primary awakenings on the average of two to three times per week. He would usually be awake around 1 a.m. and sometimes not return to sleep until 5 a.m. The parents had installed a lock to prevent the nighttime roamings, which had usually been reinforced by "raids" of the refrigerator. They would otherwise be up with him in order to stop the protests which were feared would awaken the rest of the family. No special sleep laboratory studies were needed, as further probing revealed that the father would typically return to the mobile home from his night job at around 12:30 a.m., likely awakening the boy in between stage 2 and REM transitions. Also, the boy was often permitted to play video games upon awakening, giving the awakenings an incentive value. When asked whether his protests were ever allowed to continue without adult intervention, his mother indicated that they had and he returned to sleep after 1 to 1-1/2 hours. She had apparently seen this one trial as a failure, without the knowledge that several days or weeks of ignoring his awakening would likely help him learn to remain in bed.

Wing (1966) described the irregular sleep/wake patterns in children with autism, and Howlin and Rutter (1987) reported on the high

frequency of children with autism who have either problems with sleep onset or primary awakening problems. Whether the origin lies in disturbances within the Reticular Activating System (Rutter, 1979), is related to the child's general resistance to change, or simply the result of problems of parents in communicating limits is not clear. However, learning can be facilitated with many of the children so as to improve their sleep hygiene and greatly reduce the parents' stress. Grade change methods, where systematic gradations of improvement are shaped, have been reported as a method of reducing sleep problems in children with autism (Howlin & Rutter, 1987).

Nightmares Versus Night Terrors. Sudden awakenings by the child, often in the form of screaming out in a panicked fashion, may be another concern of many parents. The critical distinction for the clinician becomes knowing whether the child is having a bad dream (i.e., nightmare) or night terror. These two different phenomena require different parental responses.

The nightmare involves a bad dream, and is a REM-stage phenomenon (see Figure 1). These usually occur during the latter part of the sleep cycle, when REM-sleep is more prevalent. The child typically does not awaken, but these fearful or sad dreams are later recalled. Parents can usually assuage the child by allowing the dreams to be repeated and to provide empathy while reflecting the child's feelings. Although studies have suggested less REM-stage duration in individuals with mental retardation (Castaldo, 1969), persons with mental retardation still have bad dreams. Verbal deficiencies may often

preclude their reporting, however.

The night terrors are an arousal disorder, also called Pavor Nocturnus. They are a Non-REM (NREM) phenomena, usually occurring between the stages 3 and 4. While images are sometimes reported by the children who experienced a night terror, no true dream has occurred. Approximately 25% of children up to about age 5 are reported to have night terrors (Guilleminault, 1987), suggesting that they are somewhat of a common occurrence in early childhood. They usually occur during the first third of the sleep schedule, when the deeper stages of sleep are more frequent. The person is not actually awake, but encounters a sudden arousal that can involve crying, screaming, flailing of the body, and apparent panic. As frightening as these are to parents, the child is usually not in much distress, and simply needs to only be protected from physical harm. The child does not need to be awakened, and does not need to "work through their bad dream". Attempts to elicit the bad dream usually only lead to understandable irritation and disruption from the child, who merely needs to resume the sleep cycle.

Excessive Sleepiness/Sleep Stage Abnormalities. A medical investigation is once again needed, whether the individual is showing excessive sleepiness during the day or oddities at sleep onset. Sleep apnea, more commonly called obstructive sleep apnea syndrome (OSAS), needs to be analyzed in order to determine whether episodes of breathing interruptions are leading to awakenings and diminished deep sleep from occurring. Sleep apnea can be a central type, also called diaphragmatic, as it implicates difficulties within the central system

that interfere with respiration. This type will usually occur in infants, and seems more common in those with prematurity or suspected CNS dysfunction. The obstructive apneas are felt to be the result of some respiratory obstruction, such as enlarged tonsils and adenoids. Individuals with excessive weight, such as is common in children with Prader-Willi syndrome, often have obstructive problems because of their weight or other factors leading to nocturnal respiratory difficulties.

Environmental factors may also contribute to disrupted sleep and daytime drowsiness. A noisy home may be disruptive to the sleeping individual, even if they are not completely awakened. One's sleep cycle is often disrupted by abrupt noises (e.g., aircraft, roommate sounds, snoring). White noise/sound attenuators, such as the use of a fan, can often be effective in preventing the intermittent sounds from being processed by the central nervous system.

The problem of sleep-onset REM stage arises in some children with mental retardation, often producing various responses. As Figure 1 shows, REM stage sleep should not be occurring until about 60 to 90 minutes after sleep begins. Even though the brain waves of stage 1 and REM stages are very similar, the increased physiological arousal and rapid eye movements of REM-stage sleep greatly differentiate it from stage 1 sleep. Individuals who begin sleep with REM might ostensibly be thought to simply be able to enjoy dreaming right away instead of having to wait. While this may be the case at times, the increased arousal can also be a hindrance to sleep onset. Furthermore, there are other children whose parents report fearfulness about the children

going to sleep because they have experienced a form of hallucinations, called hypnagogic imagery/sounds (Navelet, Anders, & Guilleminault, 1976). These are felt to be related to the brain's abnormal entry into REM-stage sleep upon sleep onset, where a mixture of wakeful and dream phenomena is occurring. In a sense, the children might be half-asleep and half-dreaming, so that the "big bear...bugs...scary monster" that they say they have seen is actually perceived by the child. The child who suddenly has become aroused and reports these occurrences right at sleep onset has likely not had a true nightmare or night terror, but hypnagogic imageries. Reassurances that their mind is playing tricks on them and letting them see that the images or sounds are not actually there (e.g., turning the lights on) is far better than trying to dismiss the sightings or just saying that they've had a bad dream. Hypnagogic imagery may occur on occasion in young children within the normal population, may be a sign of narcolepsy, or may be the result of sleep apnea. Any disruptions in the sleep schedule may also lead to the central nervous system attempting to quickly replenish the deprivation, with REM and stage 4 sleep stages showing priority treatment by the CNS.

Knowledge of this phenomenon can help in differentiating between a sleep disorder and schizophrenia. One such case was an 11-year-old girl with mild mental retardation, who reported the sighting of angels who "kept coming at" her. The concern about the onset of psychoses led to her evaluation at our Center, and it was during separate interviews with her and her parent that "the angels" were determined to occur only at night when she was beginning to fall asleep. This supported the

impression that she was experiencing hypnagogic imageries instead of signs of a thought disorder.

Conclusions

While only the tip of the iceburg of various sleep disorders in children with mental retardation has been covered, it is hoped that a few of the primary issues have been highlighted. Certainly, one could cover additional related problems from teeth-grinding to nocturnal enuresis. Several overriding factors must be emphasized whenever investigating problems around sleep. The issue of the importance for a careful interview and history-taking in the assessment must be acknowledged. Sophisticated equipment will never supplant the need for simply gathering a detailed account of the problem and related information. The clinician's knowledge of the data that currently exists in the field is also important in order to know which questions to ask and how to interpret the information obtained. Finally, the assessment and treatment of sleep disorders is probably best done within an interdisciplinary context, with clinicians from the different disciplines offering the technology and expertise within a problem-solving framework.

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